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ABSTRACT

This paper discusses the political conflicts that may arise around person-centered planning for individuals with disabilities. It argues that person-centered planning offers a forum for dealing with contested questions in the lives of particular people and in the histories of particular organizations, communities, and states. These questions concern: (1) what social roles and opportunities for economic and civic participation will be open to people with disabilities; (2) how will the work of adapting to assisting people with disabilities be divided among family members, community associations, public services and amenities, actors in the marketplace, and specialized disability services; and (3) how existing investments and practices should be regarded when they become inconsistent with changing appreciation of the rights of people with disabilities and rapidly evolving technologies for assistance. The excuses agencies use to prevent person-centered planning efforts are also discussed. The paper concludes that people who are working for real change will find themselves in the midst of political conflict and that their civic action will produce the single most reliable indicator that person-centered planning is really happening in a service system. (CR)

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THE POLITICS OF PERSON-CENTERED PLANNING

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The Politics of Person Centered Planning

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A team of regional administrators recently met an unexpected conflict with their largest service provider around a pilot project to bring self-determination to some of the people on their waiting list. With that provider's involvement and agreement, the region adopted person-centered planning as its vehicle for determining the service requirements of project participants. At the point of implementation, significant conflict arose around who would facilitate the person-centered planning process. System managers advocate that project participants choose from among a group of trained facilitators external to any service. Provider managers oppose this, arguing that their staff are experienced and capable in the techniques of person-centered planning and that participant's choice should not be limited arbitrarily, especially since a number of parents of people on the waiting list had already expressed interest in the provider's services. Because the provider agency has a strong constituency built on its tradition of local service, system managers lack the power to control the issue despite their formal authority as service purchasers. Because system managers notice that all of the provider's person-centered plans call for one or another of the services the agency already provides, most of which are typical congregate programs, they are unwilling to assign the provider responsibility for defining self-determination by implementing the process. Desiring to rise above the conflict, system managers requested assistance in locating an objectively validated standard for defining person-centered planning which would prove the necessity of independent facilitation.

Person-centered planning belongs to the politics of community and disability

To read this situation simply, as an example of the sort of conflict of interest that justifies external service coordination, would miss important lessons about the limits of person-centered planning. The most basic lesson in this: person-centered planning belongs to the politics of community and disability. It is not a way to avoid conflict about the investment of public resources; it is one way to

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creatively seek principled resolutions of real and enduring conflicts in collaboration with people with disabilities who want to consider a change in their lives that requires organized support from other people or adaptation of available service practices or policies.

Contested questions in the lives of people with disabilities

Person-centered planning offers a forum for dealing with contested questions in the lives of particular people and in the histories of particular organizations, communities, and states. These conflicts not only concern public policy, they are also integral to the politics of everyday life. Put generally, these related, conflicted questions include:

- What social roles and opportunities for economic and civic participation will be open to people with disabilities? When will people participate as clients of a disability service and when will they participate in ordinary activities and places, with accommodation and support?
- How will the work of adapting to and assisting people with disabilities be divided among…

  …family members (including extended family),

  …community associations (such as churches and civic clubs)

  …public services and amenities (such as schools and hospitals, and transit systems and parks),

  …actors in the marketplace (such as landlords, employers, co-workers, bankers, and dentists), and

  …specialized disability services?
- How will existing investments and practices be regarded when they become inconsistent with changing appreciation of the rights of people with disabilities and rapidly evolving technologies for assistance?

These political questions tend to hide in the background of person centered planning efforts. Often they hide behind two principles of practice: "We are making change one person at a time" and "We listen to the person and honor the person's choices." These slogans describe the discipline of person centered planning and are good and helpful as far as they go. They become unhelpful when they obscure the powerful effects that personal and organizational positions on political questions have on the process of person centered planning.

One person at a time can be an excuse

Focusing on one person at a time makes it possible to diversify opportunities by following different individual interests into distinct sectors of community life and allows learning about how to personalize the assistance required to fit individual circumstances. However, it can become an excuse for avoiding the administrative work necessary to make service system resources flexible and responsive to individual differences.

Position affects listening

Listening is an engaged process, not a matter of impersonally recording answers to questions like "What matters most in the way you live?" One's stand on political issues inevitably governs one's listening and problem solving. Listeners committed to shaping local workplaces to adapt to the needs of workers with disabilities will hear people's desire to find a job; listeners committed to providing a sheltered alternative to workplace demands will hear people's desire for improvements within congregate environments. Problem-solvers who believe that services exist to take the burden of care off as many families and community settings as funds allow will recognize and organize very different resources than problem-solvers who see family and community members as making an irreplaceable contribution to people's quality of life. Listeners from organizations committed to going out of the business of providing group living in favor of supporting people's lives in their own homes will hear that more people want their own places; listeners from organizations that want to offer a range of group and semi-independent alternatives will hear more desire for transfers within that range.

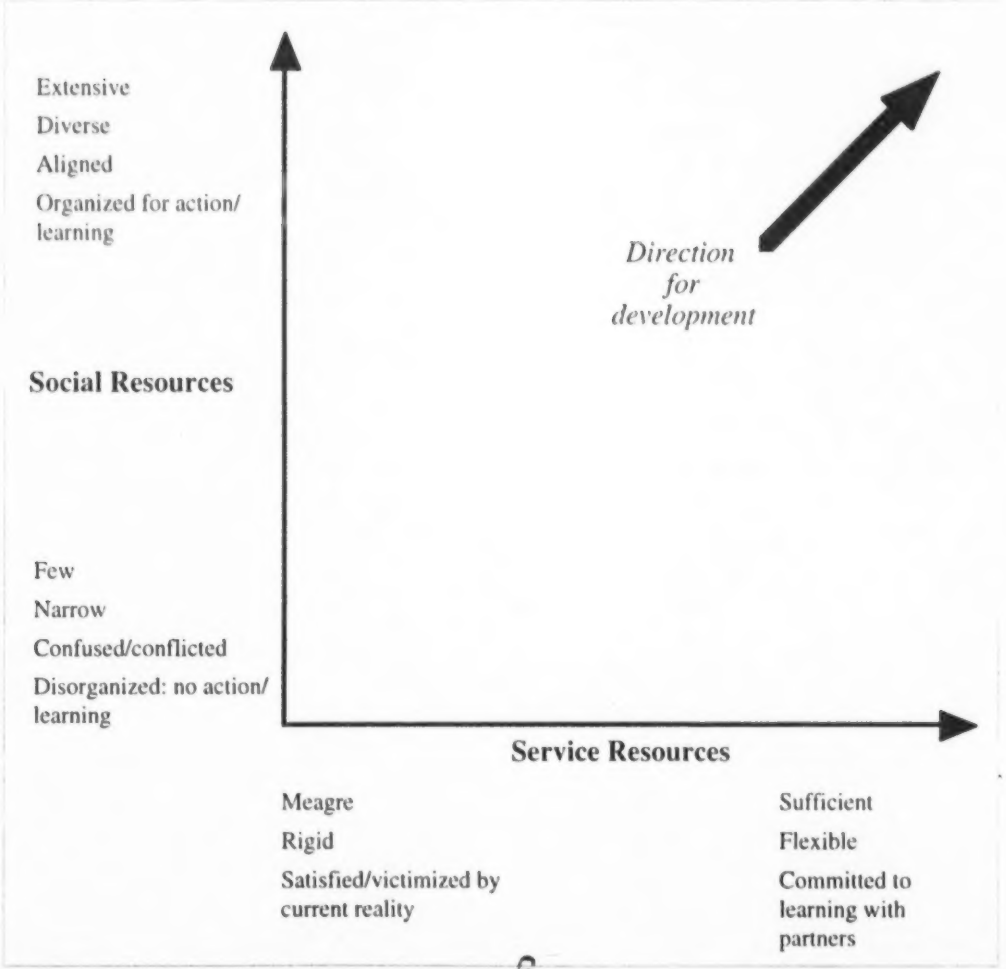
The interactive nature of listening makes the politics of community and disability inescapable, and consciousness of the effects of one's own positions essential. Indeed, reflection on what possibilities people choose to explore in one's presence can sharpen consciousness of the position one lives in. If most all the people one plans with seem pretty happy in their group homes, this suggests a definite position on the roles and opportunities that should be available to people with disabilities.

When a listener who believes that people with disabilities belong in typical workplaces meets a person who believes that they or their family member are well served in a sheltered setting, a political issue appropriately enters the process. This conflict can energize inquiry, understanding, and creative action on whatever areas

of agreement may emerge, but only if the existence of the conflict and its stakes are openly acknowledged and explored. There is no excuse for dishonoring people by leaving this conflict unspoken, though it can best find voice in respectful and civil tones. There is no objective position above the issue from which to listen, though the disciplines of suspending automatic reactions to difference, balancing inquiry about other's perceptions and beliefs with advocacy for one's own, and searching for possibilities for shared commitment are fundamental to creating the shared space necessary for effective work.

Identify resource limits

We think it good practice to orient the person centered planning process by making clear what resources are on the table as people begin. A simple framework can help clarify the space in which person-centered planning happens by allowing participants to explicit note the limitations on the process arising from the person's access to social resources and service resources.



Social resources include family members committed to their understanding of the person's well being, allies and friends who have chosen to make the person part of their own lives, memberships the person can claim, networks of contacts, information, and influence available to the person and those around the person, and the person's consequent wealth. Social resources can be more or less extensive, more or less diverse, and more or less aligned and organized for action. **Service resources** include available public funds, the capacity of service agencies to personalize assistance to people in community settings, and the interest of agencies and their staff in learning new ways to work and organize themselves in partnership with the people they plan with. Service resources can be more or less sufficient to the task, more or less flexible, and exhibit higher or lower levels of commitment and urgency. Service resources can be more or less sufficient to the task, more or less flexible, and exhibit higher or lower levels of commitment and urgency.

Person-centered planning will be weak when there is no explicit, creative, and sustained effort to increase both social resources, by supporting the person to recruit new people and try new roles, and service resources, by challenging agency and system to higher levels of personalization and flexibility. Of course, social prejudice and agency or system inertia can defeat such efforts. The reason for person-centered planning is to assure that more and more people encourage one another to try for significant change and sustain one another to keep on working despite defeat.

The best measure of person-centered planning effectiveness

People who are working for real change will find themselves in the midst of political conflict. Their civic action will produce the single most reliable indicator that person-centered planning is really happening in a service system: agency and system administrators will find themselves sweating as they deal with the uncertainties and anxieties and conflicts of fitting their organizational efforts better to the lives of the people they serve.